

A Florida Foundation Works to Ease the Emotional Scars of Vitiligo

By PRISCILLA SANTOS

Jessica Claycomb lived the first 17 years of her life afraid to go out in public. The staring and whispering of strangers destroyed her self-esteem. She chose to watch the world around her rather than take part in it. Attending college wasn't an option as she allowed her Vitiligo disease to get the best of her.

Fortunately, that's no longer the case today.

Claycomb is a student at the University of Washington, studying Arabic in Egypt and experiencing the fullness of life. She credits this positive change to a woman who works fulltime to help people like Claycomb see the beauty in themselves, despite their physical appearance.

The woman's name is Stella Pavlides, founder and president of the American Vitiligo Research Foundation Inc., which is based out of her home in Clearwater.

Vitiligo is a chronic disorder that causes depigmentation in patches of skin. It can strike any part of the body and anyone, regardless of race. The noncontagious condition alters the life of the patient physically, limiting sun exposure to avoid severe burning and blistering.

"I'm driven to make a difference in the children's lives," Pavlides said. "I have faith. And even though many days I feel I cannot go on, I still do."

The AVRF mission is to provide public awareness about Vitiligo and to make



Twin sister, Alexandra, left, and Alexis, right, attended the 2007 American Vitiligo Research Foundation retreat. Alexis has vitiligo disease, and Alexandra attends most AVRF functions with her.

a difference worldwide for those affected by the disease, focusing on children.

Finding a cure for the disease that has spread among more than 2 million Americans is exactly what she lives for, Pavlides said.

"It does not kill its victims physically, which is why no one wants to give money for research or awareness through education," she said. "But it does kill emotionally."

The 13-year-old foundation supports research at the UF College of Medicine. Gifts to the department of pathology, immunology and laboratory medicine and to the department of molecular genetics and microbiology of \$10,000 in 2003 and \$17,000 in 2004 help fund the project, "The Role of the CAT Gene in Vitiligo Susceptibility." "Gifts of \$50,000 in 2006 and \$100,000 in 2007 are funding the project, "The Role of Genetics in Vitiligo Susceptibility," in which one of the long-term goals is to determine whether at-risk individuals can be identified in

families with a history of Vitiligo. If determined, strategies for treatment and prevention of Vitiligo can be better planned.

Pavlides said she is happy to see the foundation's money fund research at UF.

"I've never dealt with researchers with so much integrity like the ones at UF, and I'm not just saying that because I live in Florida," she said with a chuckle. "I've given money to other organizations, but UF gives me back the best reports, and that's why I will continue giving money to UF. Hopefully, more people will donate, so we can continue sponsoring research at UF."